



Dear Representative,

I would like to make you aware of the appalling problem in the medical field that we have experienced in our journey with our four year old daughter Faith, who has Trisomy 18. Treatment for Faith has been withheld without our knowledge and denied, and medical providers have kept their futility policies shrouded in secrecy.

In her four short years, she has become a veteran of the medical field with five different hospital systems and dozens of medical professionals under her belt. Although we did not realize it at the time, our first experience with futility policies was with a cardiologist who had declared Faith a good candidate to have the holes in her heart repaired. At the time he first examined her, Faith was undiagnosed, but everyone knew something was wrong. Not until he received the specific results of her chromosomes test did he mention that she might not be treated and that we would now have to go to an ethics board to determine if she could have surgery. Even then, we were not told that his hospital system does not treat Trisomy 18. We have had more transparency taking our car into a mechanic; at least they are upfront with what they can and will do. They do not keep our van for several weeks telling us all the things that need to be fixed before they tell us they do not service a vehicle like ours. How much more devastating and discouraging when I take my daughter in for medical care! These undisclosed policies not to treat disabled children like Faith cost us precious time when we thought surgery was imminent and wasted money with expensive specialist appointments that would not even follow through to treat her, and severely damaged our trust in the medical community.

Doctors have withheld care from Faith by never offering care for obvious medical problems, and we did not even know what was truly going on until later. We take our daughter to the hospital in good faith that we are paying them to deliver the care they have been trained to give. No one seems to have a problem getting our payment information up front. Even in the Emergency Room, medical providers check your form of payment as they admit you. I am outraged that I have been paying for them to withhold the lifesaving treatment they would have offered to other "normal" children.

On Election Day 2010, Jesi went to get Faith up and dressed and found her eyes open and staring, and she could not even blink. She looked completely gray and the only sign of life was her chest still faintly rising and falling. What doctors neglected to even mention in two previous hospital visits for the same problem now causing this near death experience, was Faith's sleep apnea. Her small jaw was set so far back that when she slept she was not able to breathe. We almost lost Faith three times within the fall of 2010 yet not one of the many doctors we had seen at the hospitals had even mentioned her jaw or apnea being the reason for her sweating and lack of oxygen. She was gray because she had carbon dioxide poisoning caused by sleep apnea. The only reason we even knew any of this information was due to the help of another Trisomy 18 parent, former Presidential candidate Rick Santorum. When told of her symptoms, he was certain she needed a C-Pap or BiPap like his daughter Bella. Senator Santorum provided us with a list of things Faith needed. When we told the doctors other children had this treatment they told us, "nobody does that." Why were the medical providers not accountable to admit either that they are not equipped to treat or admit they have policies to not treat because they think it is futile? Finally, we wised up and left for another hospital after a veiled comment from a doctor who told us to leave. Nobody ever mentioned of a policy not to treat Trisomy 18, but we later found out the hospital has a policy not to treat. The new hospital readily and happily gave Faith the life sustaining treatment of a Bi-Pap and eventually a jaw distraction. In fact, they even asked us why the previous provider did not give Faith this needed treatment. Had the hospital been required to put their policy in writing and provide it to us, we could have avoided many hospital trips and several traumatizing near death experiences.

The Medical Good Faith Act is a safeguard for all patients and consumers requiring medical providers to make clear the standards and policies by which they operate. Making these policies known would also help reduce demands for treatment that the provider cannot or will not perform. Patients like Faith will be far better off when policies are made available and their care is demystified. Thank you for your time and help.

Keeping our faith,

Brad and Jesi Smith

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From Mina Perkins, proud mom of Mylah

Blog: <http://mylahsjourney.blogspot.com/>



Breathe Mylah.... Breathe...

Those were the 1st words I uttered to my daughter as the doctors sat her on my chest after she was ushered from my womb. Breathe.... Please.... Breathe....

I begged her to breathe. I just wanted her to utter one moan, cry, scream, anything to let me know that she was alive. Mylah was purple, her eyes wide open but no sound, no movement. That was the hardest thing in that moment. I massaged her back, tried to massage her chest like I'd seen on the many baby birthing shows I watched over the years. The room dimly lit, quiet, everyone around me seemed to disappear and it was just her and I. I begged, pleaded for her to cry. Tears formed in my eyes. After what felt like eternity, I handed her off to the nurses praying for a miracle. I felt so helpless, there was nothing I could do.

Then..... I heard it... the meek sound of my baby... She cried, not a full cry, but a small cry and it was GOD's way of showing me that he answered my prayer!

Mylah was swaddled and given back to me and we met. For the 1st time, mother & daughter; coach & fighter. She was beautiful, nothing like I could ever imagine. The moments after are somewhat a blur. Juwan and I had so much support during my labor & delivery. The hospital was phenomenal in the accommodations they made for us and our family & friends.

I arrived at the hospital Friday, March 23, 2012 at 8 am. During the first couple of hours there were some stressful moments. I had to discuss my options for delivery multiple times. I had always expressed that I wanted all measures used to help Mylah get here as best as she could. I knew that a C-section wasn't really an option due to some medical issues that I have but telling a mother whose been waiting 41 weeks to meet her 1st child is kind of hard. I finally had to realize that what my doctor wanted was what was best for my overall health and she didn't want to put me in danger of leaving the hospital worse than I arrived, so I agreed that Mylah would be delivered naturally and that a c-section was not an option. That was one hurdle for the day.

The neo-natologist arrived in my room later than morning to discuss what would happen once Mylah was born. She explained that once Mylah was born if she wasn't breathing then they wouldn't make any attempts to resuscitate her because it would be "prolonging the inevitable" and that this wouldn't make things better. I was so upset I wanted to just jump up and leave. I hated myself in that moment because I felt that I should have decided on another location to delivery my baby. I was upset because I was basically being told that Mylah if not able to breathe on her own or after being bagged would be allowed to die.....

My life was turned upside down in a matter of minutes.... I felt so betrayed, I felt so misled. I thought to myself; why develop a birth plan of what I wanted if "what I wanted" wasn't being honored. I felt no one should have the right to tell me how they were going to treat my daughter. After more discussions I had to finally accept the fact that my baby would die if she wasn't strong enough to

breathe on her own. I then expressed that I didn't want to discuss it any further once the decisions were made. I felt that my desire for a positive birthing experience was being snatched from me. I knew I was in for a long night and already I was ready for it to be over. I felt my courage and strength deteriorating but soon felt peace come over me. Whatever was going to happen was meant to be and I wasn't worried about it anymore.

During the discussions with my OB & the Walk With Me team I discussed fetal monitoring during my labor. I was aware that Mylah's heart may not have been strong enough to tolerate labor and that there was a chance that during my labor her heart would stop completely. I made it clear that if this happened I did not want to know because I knew I would not be able to handle it emotionally. We opted for intermittent monitoring of her heart. This plan worked well, the only issue I had was that each time I had to use the restroom (no bed pans for this momma) I had to unhook the fetal monitoring belts so eventually I just left the monitors off, especially once the labor pains started to intensify because I wanted to walk Mylah down. Which turned out to be a good decision and because of the number of visitors I had I never really focused on Mylah's heart once the monitors were off. There were times when the contractions started to intensify I did notice that Mylah's heart rate dropped tremendously but strangely I wasn't concerned about it.

Eventually my contractions started to pick up and I opted for the IV drugs, then the Epidural at 1:30 a.m. but I wasn't really dilated any. I was able to rest, but at 3:00 a.m. the pain started again. I thought to myself "this can't be real, I thought the epidural was supposed to help me not feel any pain" For almost a hour I withstood the pain, Juwan wanted to go get the doctor immediately but I wouldn't let him. I got the 2nd shot of medicine in my epidural around 4:00 a.m. and I was only 6 centimeters dilated. I went from 6 to full in a matter of what seemed like minutes and with 1 1/2 pushes she was out.

Born.. into this world..... into a family that loves her very much!.... to a mother & father who are willing to do what they have to in order to make sure she gets the same opportunities as any other baby.

There were so many tears of joy during this time. I think once she let out a sound everyone let out a sigh of relief.

We met some AMAZING people during our hospital stay. My 2 nurses in Labor & Delivery Carol & Kristin. Both said they'd be praying for Mylah. The nurse who bathed Mylah expressed how honored she was to bathe her and she thanked me for letting her be a part of Mylah's life for the brief moment; she left the room in tears. I wish I knew her name. Dr. Boyer who was pleasant and calming during my entire stay. There was something in her tone that let me know that Mylah was in good hands. When we were transferred to the Mother Baby unit, Heather who fed Mylah through a syringe, was so accommodating and a pleasure to meet, & finally Bobbie Anne. I don't know what to say about this woman. From our first encounter she was pleasant, funny, & caring. You could tell that she actually took pride in her job and loves what she does. Nurses like her are a God send. She took special care of Mylah and I know that they shared a special bond with each other. She was so concerned about Mylah. She

never wanted to upset her or put her through too much. She discussed everything with us. Her last night with us was very emotional. She didn't want to go and I didn't want her to leave. I felt that my daughter was safe with her. GOD truly sent the perfect person to care for Mylah in Bobbie Anne.

The Walk With Me team has been nothing but supportive. My nurse was PHENOMENAL during my delivery and there isn't anything that I can do for her to thank her enough for assisting in bringing Mylah into my world.

I still have a lot of fight in me. I've been a little frustrated lately. Being a 1st time mother is a task, but add to that load; Trisomy 18, a heart defect, lack of cooperation/understanding from medical policy makers, it makes for a pretty heavy weight. I'm grateful for my husband, parents, sisters, and the gigantic circle of friends & family that have stepped up during this time to help where they can, because the LORD knows I need it.

Mylah is doing well, Monday she had her feeding tube removed and has been bottle feeding ever since. She's sleeping well & crying even better. I know she has a nice set of lungs on her. I know that it was GOD who gave me peace in the moments when I felt defeated. It was HIM who whispered to me in the moments when I needed to make decisions regarding my health and Mylah's life. I know it was HIM who carried me during those times because there was one set of Footprints.

We are gearing up for the next leg of this race and I'm running with a wonderful team; Juwan, Mylah, and GOD running as the anchor on our team bringing us down the homestretch.



March 1, 2013

From Raffaella Castagnini, Proud mom of Maristella D'Alio

Maristella has full Trisomy 18 and is now a happy, ever smiling, curious, 38 months old toddler (DOB 12/31/09).

If we were aware of the futility policy very likely in existence at Children's Hospital of Michigan, we would have looked for treatment elsewhere from the beginning.

We would have not wasted time, money, and above all we would have not inflicted unnecessary suffering to our daughter in a likely avoidable over prolonged hospitalization.

We wasted at least 3 months in convincing the hospital to proactively treat her like a child without trisomy 18. Like her two older siblings!

Maristella was hospitalized for 6 months at Children's Hospital of Michigan and after major battling to receive proactive care, she underwent successful open heart surgery in late March 2010. In April 2010, after repetitive intubations and extubation episodes we opted for a tracheostomy to help with her unexplained and NEVER investigated breathing problems.

On July 6 2010 she was discharged and came home as ventilator dependent. We were never given a documented reason for the need of the ventilator support. One year later, July 2011, after fruitless medical appointments to solve other relatively minor health problems (for ex: the need of a cranial molding helmet and persistence of gastrointestinal problems) we switched hospital.

We were blessed to connect with other parents of Trisomy 18 children - including Jesi and Brad Smith - and without hesitation we switched Maristella's care to CS Mott where she is treated like a child that needs medical attention and not like "a trisomy 18 child"! On December 2011 we discontinued the use of the ventilator. Maristella is now a possible candidate for decannulation (removal of the tracheostomy tube).

Since her discharged in July 2010, Maristella has never been hospitalized again.

On March 1, 2010 (two years ago today) the Ethics Committee at Children's Hospital of Michigan met - we were not invited- regarding our daughter Maristella's plan of care and concluded: "Ethics Committee recommend transition to comfort and hospice care. Chance of tolerating surgery very poor. Committee willing to meet with family if requested". In a previous note they stated: "Neonatology recommended palliative care, family did not accept."

This HAS TO STOP!

Maristella is the center of our family and has touched many lives.

Respectfully,

Raffaella Castagnini